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ORIGINAL ARTICLE

Using a community of practice to develop standards of practice and education for genetic counsellors in Europe

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Abstract The profession of genetic counselling is developing in Europe in response to the increased need for genetic healthcare. Standards of education and professional practice are needed to ensure that patients are provided with genetic counselling of an appropriate quality. However, such standards need to be relevant to practitioners in many different national and healthcare settings. In order to develop appropriate standards and a code of practice to guide professionals in Europe, we formed a community of practice that includes genetic nurses and counsellors, plus other interested health professionals, from 23 European countries. With reference to the European core competences for genetic counsellors, the members of the network developed a set of professional standards for practice, educational standards and a code of practice. It is strongly suggested that the title genetic counsellor should become a protected title in Europe and that practitioners are educated via a master level degree in genetic counselling. These standards have been approved by the members of the network and the existing professional national societies for genetic nurses and counsellors. They provide a foundation for building the profession of genetic counselling in Europe and for provision of equitable care across European countries. Further work is now needed to ensure that appropriate educational opportunities exist to train practitioners and that clinical teams utilise the expertise of these professionals appropriately to enhance the care offered to families at risk of or affected by genetic conditions.

Keywords Genetic counsellor · Professional standards · Education · Competence · Europe · Code of practice

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Background

Genetic counselling is defined as an activity involving provision of information about the genetic condition, recurrence or carrier risks and options for prevention or management of the condition (Kääriäinen et al. 2008). However, it also involves psychological support of clients, especially during periods of crisis and/or decision making (Rantanen et al. 2008). Many health professionals may undertake these types of activities as a part of their work with patients, but for a genetic counsellor, they are the central focus of the work undertaken with families at risk of or affected by a genetic condition. Where genetic healthcare is provided by multi-disciplinary teams, genetic counsellors often provide continuity of care to multiple family members through contact with them over months or years. As genetic counselling requires clinical skills, many practitioners have a professional background and qualification in nursing, midwifery, social work or psychology (Skirton et al. 2003). However, others without this background may prepare for practice by undertaking a suitable period of training, such as a master's degree in genetic counselling (Skirton et al. 2003).

In Europe, there is a range of healthcare systems and professional traditions existing in different countries, and the use of genetic counsellors varies greatly. For example,

in the United Kingdom, genetic counsellors are a part of the multi-disciplinary team in every genetic centre and a formal registration system for genetic counsellors has been in operation since 2001. At present, the registration is not mandatory, but it will become so when the profession is statutorily regulated within the next few years through the (Health Professions Council 2009). Genetic counsellors and/or genetic nurses currently practise in a range of countries including the Netherlands, France, Spain, Portugal, Norway, Finland, Sweden, Denmark, Switzerland, Cyprus, United Kingdom and Belgium. In contrast, there are no genetic counsellors working in some countries (such as Germany, Russia, Poland and Lithuania) at present.

The work described in this paper was initiated as part of the EuroGentest project, a European project to harmonise and standardise genetic counselling across Europe. One of the key recommendations of that project stated that families and patients should routinely be offered appropriate counselling when having a genetic test, particularly in the case of presymptomatic and prenatal tests (Kääriäinen et al. 2008). There are limitations to the numbers of patients that can be seen by medically trained geneticists. In some countries, laboratory trained staff undertake genetic counselling to accompany testing, but they may not have the clinical background or specialist training in communication skills to enable them to fulfil this role appropriately for patients. Genetic counsellors have a role to play in provision of counselling to accompany genetic tests and should be educationally and professionally prepared to undertake these tasks.

In acknowledgement of the importance of ensuring adequate standards of patient care provided by genetic counsellors, the European Society of Human Genetics (ESHG) sets up an Ad Hoc Genetic Nurse and Counsellor Accreditation Committee. The overall aim of the committee is to achieve European recognition for genetic counselling as a profession. The initial objectives were to build foundations for the profession setting standards of professional practice and education. In the multinational European context, it is important to create standards that are rigorous in terms of quality of care while also being adaptable to national legal and health service frameworks.

Methods

In order to ensure feasibility and equity of genetic counselling practice in different countries, it was essential to agree a set of professional standards using the expertise and experience of those actually working in the profession. We considered that one method of making contact with genetic nurses and counsellors in different countries was via their professional societies. However, in many countries, the numbers of genetic nurses and counsellors is very low, and professional organisations for those practitioners are nonexistent. We therefore decided to form a network of genetic nurses and counsellors working in Europe, plus other interested and supportive professionals. This enabled us to form a community of practice, which is suggested by Ardichvili et al. (2003) as a method of enabling members of a specific group to contribute to discussion and development in an area of interest, despite geographical constraints. The network was widely advertised through the ESHG and all past students of the European Genetics Foundation courses. All those registering interest were asked to circulate details of the network to colleagues and contacts working in genetic healthcare. There was no fee to join. Current members of the network number 156 members from 23 countries. The network conducts business by electronic means, using a website (http://www.engnc.org/) and regular newsletters circulated by email. Business is conducted in English, but where this would exclude members from some countries from fully participating, information is translated by a member from that specific country and circulated. The network operates under the auspices of the Ad Hoc Genetic Nurse and Counsellor Accreditation Committee of the ESHG.

After formation of the network in 2008, those members that were able met at the annual scientific meeting of the ESHG and shared their experiences. The 33 members present decided that there were three priorities for the community of practice: to establish standards for ethical and safe practice, to determine minimum educational standards for genetic counsellors and to establish a website to facilitate communication. Members of the network were asked to volunteer for work on the three working groups set up to ensure these issues were addressed. Initially the working groups for practice and education worked separately, but it quickly became clear that these were so inextricably linked that it was sensible to approach them together.

The set of core competences for genetic counsellors had been developed through a process of wide consultation during the EuroGentest project (Skirton et al. 2010), and these were used as a foundation for the professional practice and educational standards. Initial drafts of the standards were written by the working group members, and these were circulated to all members for comments. In November 2009, members from the working groups met in Paris to progress the work, and the standards were refined. In addition, a draft code of professional practice for genetic counsellors practising in Europe was written. Following more consultation with all members of the network, slight modifications were made, and the members were asked to vote to register their approval or disapproval of the documents. The members voted overwhelmingly to approve the standards and the code of ethics presented below.

Table 1 Code of professional practice for genetic counsellors in Europe

The genetic counsellor will:

1. Respect the human rights of the client, in accordance with the recommendations of the World Health Organisation.
2. Work in accordance with the legal and ethical requirements of the setting and country in which he or she practices.
3. Enable equality of access to services, without discrimination on the basis of ethnicity, religion, belief, gender, disability, age or sexual orientation.
4. Protect confidential information obtained in the course of professional practice and obtain the client's consent to disclose information to other professionals and/or family members.
5. Offer accurate information on the range of options available to clients, while respecting the right of the client to make decisions based on their own beliefs and values.
6. Enable clients to make informed decisions, free from coercion.
7. Avoid any abuse of the professional relationship with clients.
8. Maintain clear, contemporaneous and accurate medical records.
9. Collaborate and co-operate with colleagues to achieve standards of good clinical practice.
10. Act as an advocate for service users, as appropriate.
11. Act appropriately to report concerns about the safety of clients and/or quality of care.
12. Be aware of his or her own physical, mental and emotional health and take action to prevent adverse impact on practice.
13. Participate in clinical and counselling supervision.
14. Be aware of his or her personal beliefs and limitations of expertise and refer clients as appropriate to ensure they have access to the full range of services and decision options.
15. Maintain his or her own knowledge and skills through continuing professional education.

Results

Protected title

At present, any person can state that they are a genetic counsellor, without any legal ramifications. This situation may expose patients to unsafe practice. To ensure that those using this title are appropriately educated and competent in this specialised field of practice the Ad Hoc Committee for Accreditation of Genetic Nurses and Counsellors has proposed that the professional title 'genetic counsellor' should become a protected professional title in Europe.

Definition of the profession of genetic counsellor in Europe

The Committee has suggested that the following definition of a genetic counsellor is adopted in connection with the protected title:

> 'A genetic counsellor is a health professional who has undertaken a period of education and training at master level to enable them to develop the necessary competences to fulfil the role, as described below. It is envisaged that in the future (by 2020), the standard training and education for a genetic counsellor will be the master's degree in genetic counselling. However, practitioners who have been formally assessed as having the necessary competences at master level and are accredited legally as genetic counsellors in their own country will also be eligible to use the title ' genetic counsellor' in Europe.'

Standards of education and training

The aim of the education and training for genetic counsellors is to:

1. Ensure that genetic counsellors have the relevant competences to practice appropriately in relevant clinical settings
2. Enable genetic counsellors to develop skills in critical appraisal of evidence that will inform service provision
3. Provide genetic counsellors with an appropriate scientific and research training to facilitate the development of a body of research evidence in the field.

Genetic counsellors are required to have the competences described by the ESHG for genetic counsellors (Skirton et al., 2010). In order to acquire those competences, the practitioner is required to undergo a period of specialised education and practical training. In accordance with the level of expertise, theoretical knowledge and clinical skills required to develop the prescribed competences, the minimum standard of training and education for a genetic counsellor will be a programme leading to the award of a master's degree in genetic counselling. Each educational institution will need to structure such a programme according to their own regulations; however, it should include:

- Human genetics (Mendelian and non-Mendelian genetics, cytogenetics, basis knowledge of molecular and biochemical principles and genetic risk determination)
- Medical genetics and clinical aspects of human genetic disease, for example metabolic disorders, congenital malformations, cancer syndromes, multifactorial disorders and mental retardation
- Counselling skills training, including theoretical models to underpin counselling practice, practical skills development and exercises to enhance awareness of the impact of the counsellor's personal history on the process
- Preparation for working in a range of clinical areas, including prenatal, paediatric and adult services in both hospital and community settings

Table 2 Organisations for genetic counsellors and/or genetic nurses in Europe

Country	Organisation	Website
France	Association Francaise de Conseilleurs en Genetique (AFCG) [Association of Genetic Counsellors]	http://asso.orpha.net/AFCG/cgi-bin/
Norway	Norsk interessegruppe for genetiske veiledere [Norwegian National Association of Genetic Counsellors]	No website
Sweden	Swedish Association of Genetic Counsellors	No website
The Netherlands	Nederlandse Vereniging Genetisch Consulentten (NVGC) [Association of Genetic Counsellors]	http://www.nvgc.info/
United Kingdom	Association of Genetic Nurses and Counsellors (AGNC)	http://www.agnc.org.uk/
Europe	European Network of Genetic Nurses and Counsellors (ENGNC)	http://www.engnc.org

- Material on psychosocial issues, including the impact of genetic conditions and genetic testing on the individual and family
- Ethics, law and sociology studies relevant to genetic counselling practice.

Due to the clinical nature of the profession, the educational programme must include substantial practical experience in a clinical genetics and other relevant settings and research training.

Genetic counsellors work in a multi-disciplinary environment, and the education and training should reflect the involvement of many disciplines required for the development of competence and effective professional working. While the primary teachers and mentors for trainee practitioners must be qualified and experienced genetic counsellors, substantial practical and theoretical contributions will be required from other relevant professionals to ensure the training is comprehensive. In addition, the perspectives of service users and patient support group representatives will be vital.

Role of the genetic counsellor

It is recommended that the role of a genetic counsellor in the European context should include the following aspects of practice:

- To identify the needs of the individual or family and use an empathic client-centred approach to the provision of genetic counselling
- To collect, select, interpret and analyse information (including family and medical history, pedigree, laboratory results and literature) relevant to the delivery of genetic counselling for individuals or families
- To help people understand and adapt to the medical, psychological, social and familial implications of genetic contributions to disease
- To assess the chance of disease occurrence or recurrence
- To provide education about inheritance, testing, management, prevention, resources and research to relevant individuals or families
- To promote informed choices and psychological adaptation to the condition or risk of the condition
- To apply expert knowledge to facilitate the individual or family to access the appropriate healthcare resources, including a medical diagnosis and resources for management of the condition.

Code of practice

The code of practice agreed by the members of the network and the five national societies for genetic nurses and counsellors that currently exist in Europe is presented in Table 1.

After approval by the network members, all of the documents were sent to leaders of the national professional societies for genetic nurses and counsellors that exist in Europe; these are in the Netherlands, France, Norway, Sweden and the United Kingdom. All those societies approved the standards.

Discussion

The formation of a network of professionals has been effective in creating a community of practice (Wenger et al. 2002). Communities of practice have been shown to be effective in motivating members to make meaningful contributions to the group around which the community is built, especially when the members are united by a desire to improve a situation for the common good (Ardichvili et al. 2003). In this case, there was significant input into the standards by experienced practitioners from a wide range of countries and practice settings, as well as from individuals working in education and research. Comments and opinions were also widely sought and, after due consideration, changes were made to the draft standards in response to these. The network is large and includes members from 23

countries, but it is possible that not all those practising genetic counselling in Europe have had an input into the development of the standards. However, efforts have been made to enable input through wide advertisement of the network, posting of the standards on accessible professional websites and through feedback from the relevant national societies (Table 2). It could be argued that due to the wide advertisement of the network, those who joined the community of practice were likely to be those most interested in the development of the profession and therefore most likely to wish to contribute to the project.

Other professional organisations have published code of ethics (Association of Genetic Nurses and Counsellors 2001; National Society of Genetic Counselors 2006). Because of the nature of the profession, naturally many themes and issues represented in those codes of ethics are also mentioned in the European code of practice. However, the previously existing codes of ethics for genetic counsellors have been devised for professionals drawn mainly from single nations, and it was important to ensure that these were not simply adopted for European use. The community of practice worked to produce a code of practice that addresses the relevant issues without inhibiting use in specific national contexts. The EuroGentest project was originally designed to harmonise practice across Europe. The development of common agreed standards as described is an important outcome from this project.

These standards have been developed by practitioners in genetic counselling; however, services are provided by multi-disciplinary teams, and it is essential that they are consistent with the ethos and delivery of genetic health services in each country. Further consultation is therefore required with other relevant health professional groups. Ultimately it will be the responsibility of practitioners in each country to utilise the standards in ways that reflect the requirements of their own healthcare systems.

In terms of educational standards, a challenge exists in ensuring that potential practitioners have access to training in genetic counselling at master level with the necessary clinical exposure and specific in-depth training in counselling and communication skills. It may not be possible to offer such programmes in each country, and opportunities for distance learning for the theoretical aspects, with local practical placements, could be explored as one alternative to traditional degree programmes.

Conclusions

Using a community of practice has been effective in facilitating relevant standards for training and practice of genetic counsellors. These provide a foundation for building the profession of genetic counselling in Europe and for provision of equitable care across European countries. In June 2010, the standards were presented to the Board of the ESHG and to the meeting of presidents of all European national professional genetics societies.

Further work is now needed to ensure that appropriate educational opportunities exist to train practitioners and that clinical teams utilise the expertise of these professionals appropriately to enhance the care offered to families at risk of or affected by genetic conditions.

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